

# DIVISION OF DISABILITY SERVICES

# VISIONS

Volume 2, Issue 1

April 2002

William A.B. Ditto, Director

## *McGreevey Names Harris to Lead Human Services*

Governor James E. McGreevey has announced his top choice to lead the Department of Human Services.

Gwendolyn L. Harris, who has served the City of Trenton for the past 12 years as Chief of Staff to the mayor, Business Administrator and Director of the Department of Health and Human Services, has been named the Commissioner of Human Services.

As head of DHS, Harris will bring more than 20 years of experience, leadership skills and knowledge with her. Previously, Harris was Program Director for Newark's New Community Corporation and Assistant Regional Administrator for the Central Region of the Division of Youth and Family Services (DYFS).

"In over 20 years of dedicated public service, Gwendolyn Harris has demonstrated that she is capable of not only leading New Jersey's Department of Human Services, but of leading it in the right direction," said McGreevey. "She has seen first hand, from the inside and the outside, how the department runs, and she has a strong commitment to making it run better."

*Harris, continued on page 3*

## *"Hello, Hold for a Certified Information and Referral Specialist."*

### **Information and Referral Staff Receive National Certification**

Division Director William Ditto is pleased to announce that all three members of the DDS Information and Referral Staff have become Certified Information and Referral Specialists after passing the national examination.

Administrator Joseph Amoroso and Information Specialists Christine Cripps-Barker and Marlene L. Hester spent the better part of a year preparing for the exam and completing the service requirements. "It was a lot of work, but it was worth it. It will certainly help us to assist our callers more efficiently," says Hester.

The Association of Information and Referral Systems (AIRS), the organization granting certification, is a national professional association for providers of information and referral services. Presently, there are six other professionals who hold this certification in New Jersey. ♦

## *Volunteers Bolster I&R Staff*

The Information and Referral staff is pleased to welcome new volunteers Nicole L. Davis and Nancy L. Mangold aboard. Both Ms. Mangold and Ms. Davis will serve as support staff to the professional I and R Staff.

Ms. Davis, a person with Spina Bifida, is no stranger to the disability field, working professionally as the Urban Outreach Coordinator for the Progressive Center for Independent Living (PCIL). She is a graduate of Rider University.

Ms. Mangold, a graduate of Stockton State College, is making her first venture into the disability services field. She is a person with Multiple Sclerosis ♦

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## SAVE THE DATE

### March

- Developmental Disabilities Awareness Month
- Hemophilia Month
- Mental Retardation Awareness Month
- National Chronic Fatigue Syndrome Awareness Month
- National Kidney Month
- National Nutrition and Colorectal Cancer Month

### April

- Cancer Control Month
- National Occupational Therapy Month
- April 12-14 **Abilities Expo.**  
Raritan Convention Center, Edison NJ
- April 23 **Statewide AIRS-NJ Conference.**  
Center for Health Affairs, Princeton, NJ

*The Division of Disability  
Services will be at the  
Abilities Expo  
April 12-14, 2002  
Booth # 1345*

*Visit our website!*

The Division of Disability Services is on the  
Internet at:

<http://www.state.nj.us/humanservices/dds/>

### CORRECTION POLICY

It is our policy to correct all significant errors. If you believe we have made such an error, please contact Joseph Amoroso at the Division of Disability Services, (609) 292-7800, or write to him at P.O. Box 700, Trenton, NJ 08625-0700.

# VISIONS

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**Honorable James E. McGreevey**, Governor

**Gwendolyn L. Harris**, Commissioner, Department of  
Human Services

**William A.B. Ditto**, Director, Division of Disability  
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**Joseph M. Amoroso**, Supervisor, Information and  
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Specialist

**Marlene L. Hester**, Information and Referral Specialist

**Kristy Ahrlich**, Intern, Information and Referral

**Nicole L. Davis**, Volunteer, Information and Referral

**Nancy L. Mangold**, Volunteer, Information and Referral

### CONTRIBUTIONS

We welcome contributions from New Jersey disability service providers and organizations. If you would like to contribute to subsequent issues of this newsletter, please contact Joseph Amoroso at the Division of Disability Services, P.O. Box 700, Trenton, NJ 08625, or fax information to (609) 292-1233.

## Personal Assistance Services Program Adds New Self-Care Certification Component

**Michael A. Nuskey**  
Program Manager, PASP  
Division of Disability Services

The Personal Assistance Services Program (PASP) implemented an optional service component that allows eligible consumers to incorporate routine self-care tasks into their plan of service.

In January 2002, PASP consumers received notification of this new component and were given an opportunity to have personal assistants from county agencies perform their self-care tasks. This component was developed by the Division of Disability Services, in cooperation with the PASP Consumer Advisory Council, in response to consumers who need routine assistance with self-care procedures but are without resources and/or family members to perform such tasks. The component is based upon a review of current policies in several states, whereby certain restrictions were eliminated to enable consumers with disabilities the ability to manage and supervise their self-care tasks and thus lead more productive lives.

In order to implement this component, the Division approached the New Jersey State Board of Nursing for an amendment to state regulations to permit personal self-care tasks that are currently performed by nursing professionals to be performed by qualified personal assistants under the supervision of a self-directed PASP consumer. The Division successfully negotiated an agreement to permit a process of consumer certification that allows an incorporation of routine self-care procedures into their service plan without any violation of the New Jersey Nurse Practice Act.

The consumer certification component requires the completion of an assessment by a registered nurse, which is designed to evaluate the consumer's level of understanding in completion of self-care tasks and the capability to instruct and supervise the performance of those tasks by a personal assistant. Upon receiving certification by a registered nurse, the consumer shall assume all responsibilities for the performance of the tasks. The consumer certification process requires a re-certification every twelve months to enable a continuation of self-care services. The performance of any self-care services by a personal assistant, without the approved consumer certification, is in violation of the state Nurse Practice Act.

PASP consumers who are interested in managing and

supervising their self-care procedures must contact their local county PASP agency coordinator for an application and further information. All applications for consumer certification will require approval by the Division of Disability Services. ♦

### *Harris, continued from page 1*

"She is a proven administrator, with the experience necessary to lead a department that has such a tremendous impact on the lives of our children, families, the disabled and our senior citizens."

Currently, Harris is pursuing her Ph.D. in Urban Planning and Policy Development at the Bloustein School of Planning and Public Policy, Rutgers University. She already holds a B.A. from the University of Connecticut and a Masters from the School of Social Service Administration at the University of Chicago.

Harris has been a member of the New Jersey Public Policy Research Institute since 1981 and has served as President, Vice-President and Secretary of the Board. She also serves on the Board of Trustees for the AIDS Resource Foundation for Children and on the Local Government Advisory Board for the New Jersey Department of Personnel. Harris formerly served on the Board of Directors for the Newark League of Women Voters, and on the Board of Trustees for the Community Foundation of New Jersey. ♦

### **Other McGreevey Cabinet Choices**

Holly Bakke	Banking & Insurance
Bradley M. Campbell	Environmental Protection
Ida L. Castro	Personnel
Jeanne M. Fox	Public Utilities
David Samson	Attorney General
Albert G. Knoll	Labor
Charles M. Kuperus	Agriculture
Clifton R. Lacey, MD	Health & Senior Services
James P. Fox	Transportation
Susan Bass Levin	Community Affairs
William L. Libera, Ed.D.	Education
Devon Brown	Corrections
John E. McCormac	Treasury
Col. Glenn K. Reith	Military / Veterans Affairs
David Samson	Law & Public Safety
Joseph J. Santiago	State Police
Seema M. Singh	Public Advocate
Regena Thomas	Secretary of State
Rev. Dr. William Watley	Commerce and Economic Growth

## ***How to Handle a Problem with Your Managed Care Plan***

More and more New Jersey residents are getting their health care through a managed care plan. In fact, over 3.5 million state residents are now members of managed health care. The majority report that they are satisfied with their managed care plan, and the health care received from their plan. But, as happens, managed care plan members can have a problem with their health care plan, and are often unsure of what steps to take in order to have that problem or question addressed.

### **You Have a Right to Complain**

In New Jersey, members of managed care plans have the right to file a complaint with their plan regarding any concern they might have with the plan's health care services. This provision applies to commercial or private coverage, as well as Medicare or Medicaid (These grievance and appeal rights do not apply to health care plans that are "self-funded" or "self-insured" by an employer or group. Be sure to ask your employer what type of plan you have. The process for appealing a health plan decision or filing a grievance is different if you are a member of a plan that is classified as "self-funded" or "self-insured"). The complaint process is known as filing a grievance. Some common problems about which members complain include not being able to get an appointment, unhappiness with a health care provider's attitude, receiving inadequate medical care, and other such "quality of care" issues.

Every managed health care plan must provide its members with written information about how to file a complaint. You should find this information in the member handbook provided by the plan, or in a separate document from the plan. There are certain steps you should follow in order to file a complaint with your managed care plan. First, think about whether or not a conversation with your primary care physician could solve the problem. For example, if you are unhappy because you were kept waiting a long time for an appointment, find out from the doctor if there was a reason why you had to wait, such as an emergency.

If your doctor cannot provide a satisfactory answer to your problem, or it is inappropriate to speak to your doctor because of the nature of the problem, call your health plan's Patient or Member Services Department in order to file a complaint. You should find the telephone number in your Member Handbook or on your insurance card. The managed care plan then has up to 30 days to respond to your complaint. If you are unsatisfied with the answer you get from your health plan, you can contact the New Jersey Department of Health and Senior

Services for complaints relating to quality of care issues, or the New Jersey Department of Banking and Insurance for grievances concerning the business practices of a managed care plan.

### **You Have a Right to Appeal Managed Care Decisions that Deny, Terminate or Restrict Covered Health Services**

If your managed care plan denies, terminates, or limits health care services, or denies payment for any health care services covered under the plan, you have the right to appeal that decision under New Jersey law. Either you, as the member, or your doctor, with your consent, can file an appeal.

There are three stages to the appeal process. The first stage, called "the informal internal appeal", allows you to get a review of the denial, limitation, or termination of the covered health service by the health plan. To initiate this first level of appeal, you can call the health plan and ask for a reconsideration by the medical director or the physician who made the decision. If you file this appeal by phone, it is a good idea to always follow up with a letter. The managed care plan has five business days to respond to this appeal, or three days in the case of an emergency.

If the stage one appeal is not decided in your favor, by law the managed care plan must provide you with information on how to proceed to the second level of appeal, known as the formal internal appeal. This appeal level also is filed with the managed care plan. You should file in writing, and include a detailed description of exactly what you want and why. In order to maximize the possibility of a successful appeal, include information about why you need the particular health service in dispute. If possible, get your doctor to include the reasons why the health service you seek is medically necessary. The managed care plan must answer this second stage appeal within 20 business days, or three days in emergency cases. Send all correspondence by certified mail, return receipt requested.

If a stage two appeal is denied, the managed care plan must give you written notice detailing the reasons for denial, as well as an explanation and forms necessary for the third level of appeal. This final appeal stage is known as the "External Appeal." This appeal is made to the New Jersey Department of Health and Senior Services, which in turn refers your appeal to an Independent Utilization Review Organization (IURO). You must file this third stage appeal within 60 days of the time the stage two appeal decision was finalized by the managed care plan.

***Care, continued on page 13***

## ***Model Waiver Increases My Quality of Life***

**Marc Grayson**  
Alpine, New Jersey

I have always heard that life is made up of moments. Well, I guess you could say that my life came down to one moment. In December of 1997, I was involved in a car accident. The accident was pretty bad, and I am lucky to be alive. I did, however, sustain a C5-C6 Spinal Cord Injury making me a quadriplegic.

While in rehab, I wondered how my personal care needs would be met. Could I live in the community? Would I be forced into a nursing home? As a young man, the thought of a nursing home did not thrill me. I became depressed and despondent.

My social worker began talking to me about a Medicaid Waiver that could pride me with the level of service that I needed in the community.

To be honest, my first thought was that this is too good to be true, but I am happy to say that I have been on the Model Waiver since my discharge from rehab, and with its services I am doing great. I receive 8 hours of personal care assistant services a day, seven days a week, and 4 hours of skilled nursing service a day, seven days a week. The staff that serve me are priceless! They assist me with my personal hygiene, meals, and medical care regime to ensure that I stay healthy. Additionally, I have a case manager who is always available to help me resolve any problems or glitches.

Thanks to the Model Waiver, I don't have to worry about how my personal care needs will be met. I can focus on other things that I enjoy doing, like spending time with my children, ages 14 and 10, listening to music, and surfing the net with my modified computer. My family and friends do help me (special thanks to my brother and the Alpine Police Department for their help with my transfers), but because of the consistent professional help I receive, I don't feel like a burden and they don't get burned out.

My life has changed in many ways since my accident. Often it seems like a lifetime away. It's easy to reflect on what was lost, but I prefer to focus on what I have. The Model III Waiver has increased my quality of life by allowing me to remain a parent and a person. I am reminded of this each time my children visit, and we watch videos at my house rather than in the community room of a nursing home. ♦

## ***My Hero Has Four Legs***

**Javier Robles**  
Deputy Director  
Division of Disability Services

Heroes come in all shapes and sizes - some drive big red trucks and fight fires and others have as their mission to "serve and protect." However, some heroes perform daily duties without recognition or medals. They are the uncommon heroes, otherwise known as assistance dogs. These dogs provide independence for individuals with a variety of disabilities.

The hero in my life died two years ago. Tess, a female yellow Labrador Retriever, was trained by Canine Companions for Independence (CCI), the founder of the assistance dog movement. CCI was the first organization to train dogs to serve individuals with disabilities other than blindness. Since 1975 when CCI opened its doors, there have been several other organizations that have taken on the challenge of providing service dogs to individuals with disabilities.

Tess and I began our journey together after graduating from two weeks of intense training at the CCI facility located in Farmingdale, NY. I was at a disadvantage since Tess had already been trained for two years before I got there for my two weeks. Her tenure with me began while I was a counselor at Rutgers University. I noticed how independent she made me feel the first week I had her. I no longer needed to call co-workers to come to my office and pick up things that I had dropped. In addition, Tess would retrieve papers from the photocopy machine as well as turn the lights on and off. She would open doors and retrieve folders from the filing cabinet.

Tess came into my life at a time when I married Amy and we had just received custody of my nephew Giovanni. Tess fit in perfectly to our busy and hectic lifestyle. Amy was attending graduate school at the time and Giovanni was in daycare, so Tess provided Amy with a sense of safety and me with true independence. When I was home alone, Tess was my personal care assistant. She would pick up dropped remote controls, notebooks, pencils or pens. In addition, she could get my lunch from the refrigerator and place it on the table.

On one occasion, when Amy had gone to school, I fell over onto my side in my power wheelchair. As a quadriplegic, once I fall over, it's difficult or sometimes impossible for me to get upright because I have no control over my stomach and chest muscles. Realizing that I was in trouble, I gave Tess the command to bark for assistance and she did for almost an hour.

***Hero, continued on page 19***



## RESOURCE SHELF

### ***“Working Together” Is Useful Resource for Supported Employment Providers***

**Marlene L. Hester, C.I.R.S.**

Information and Referral Specialist  
Division of Disability Services

In their book Working Together: Workplace Culture, Supported Employment, and Persons with Disabilities, Hagner and Dileo address the challenges of job coaches trying to develop effective work site supports for their clients by encouraging them to understand a workplace as a culture. “Becoming a success at a job does not consist solely in learning to perform a sequence of tasks,” they assert, but in participating in the “norms related to giving and receiving support.”

The authors encourage the supported employment provider to recognize situations in which positive interpersonal relationships in the workplace may motivate the employee and enhance performance and confidence, ultimately increasing the likelihood that the placement will be successful. They feel that the main reason for the drift away from previously popular employment models (such as sheltered workshops and work crews) for people with developmental disabilities is that these segregated environments can prevent employees from doing meaningful work, earning competitive wages, or developing fulfilling workplace relationships.

The book guides the reader to see ways in which social connections may increase the morale and satisfaction of the employee. Hagner and Dileo give the example of a supported employee who worked in an office in which the staff regularly gathered after work each Friday at one of several local pizza parlors. Someone would select that week’s location early on Friday, then go around and inform everyone else in the office. Those away from their desks had notes left on their chairs. This particular employee used a wheelchair, so when she left her work station she took her chair with her, and was therefore being inadvertently left out of the communication loop. This employee very much wanted to be included in this custom, so the solution that was ultimately devised was that she would leave a little pizza box out on her desk so that her co-workers would know that she wanted to go out with them and would have a place to leave her notes. Her system was a success, and other employees with cluttered workspaces even adopted the pizza box method themselves so that their own notes would not get lost. ♦

The book goes on to offer assistance in dealing with challenging situations not necessarily addressed by the prevailing “job coach model” (analyzing the task, teaching the task, prompting, fading, keeping data). What is a supported employment specialist to do when dealing with a workplace that expresses fellowship by teasing, when the supported employee is hypersensitive to being taunted? The authors practically address this and many other dilemmas, emphasizing the overlooked but unavoidable reality that social belonging is a necessary part of any successful placement. Supported employment providers in search of fresh perspectives will find this book to be a valuable resource. ♦

Working Together: Workplace Culture, Supported Employment, and Persons with Disabilities.  
David Hagner and Dale DiLeo. Brookline Books, 1993.  
ISBN 0-914797-88-3.

***Resources, continued page 18***

### ***WDHCSC Forms Work Groups***

**Christine Cripps-Barker, C.I.R.S.**

Information and Referral Specialist  
Division of Disability Services

Women with Disabilities Health Care Steering Committee (WDHCSC) has formed four work groups to address issues identified at their Summit in June, 2001.

The four work groups, comprised of 21 women with disabilities from across the State of New Jersey, will be:

- Publications-Media, chaired by Paulette Eberle (Hudson County)
- Legislative-ADA-Advocacy, chaired by Christine Fraser (Union County)
- Research Agenda, chaired by Christine Cripps-Barker (Camden County)
- Wellness-Preventive Care, chaired by Janice Ortiz. (Union County)

The workgroups are charged with identifying issues that affect women with disabilities in order to address research priorities and to influence the treatment they receive from health care providers.

A copy of the report from the Summit can be obtained by contacting Pat Krupka at 609-984-4513 or via email at [pat.krupka@njddc.org](mailto:pat.krupka@njddc.org). ♦

### ***Tingus Appointed Director of NIDRR***

U.S. Secretary of Education Rod Paige recently announced that Steven James Tingus will serve as Director of the National Institute on Disability and Rehabilitation Research (NIDRR). NIDRR includes the Education Department's Interagency Committee on Disability Research, Research Sciences Division, and Program Development Division.

As Director, Tingus will serve as chief advisor to Assistant Secretary for Special Education and Rehabilitative Services Robert Pasternack and direct research programs and activities related to maximizing employment and independent living opportunities for disabled individuals of all ages.

In addition, Tingus will manage all NIDRR activities, including the preparation of a long-range plan for rehabilitation research, direct funding and resources for research and training centers, evaluate current and future operating programs, and disseminate new research related to disabilities and effective rehabilitation policies and practices.

Prior to joining the Education Department, Tingus served as Director of Resource Development and Public Policy, and as Director for Assistive Technology at the California Foundation for Independent Living Centers. In that latter capacity, Tingus developed and implemented model policies and activities to broaden access to assistive technology for people with disabilities to help them live independent and productive lives.

From 1995 to 1998, Tingus served as a health care policy analyst in the Office of Long Term Care at the California Department of Health Services. He earned his Master of Science degree in physiology from the University of California, Davis, in 1990 and has done work toward his doctoral degree in physiology. ♦

*Reprinted from New York Able Newspaper, December*

### ***SSA Announces Increase in Payments***

Acting Social Security Commissioner Larry G. Massanari announced a 2.6 percent increase in Social Security and Supplemental Security Income (SSI) payments. The Cost-of-Living Adjustment (COLA) will begin in January 2002 for people who receive Social Security. For people who get SSI, the increase will start on December 31, 2001. "(The) news tells us that inflation continues to be low which is certainly good news for the elderly and disabled," said Acting Commissioner Massanari. "Inflation is one of the biggest challenges for people living on a fixed income." To learn more about the new Cost-of-Living Adjustment, see the News Release at [www.ssa.gov/pressoffice/colapress2001.htm](http://www.ssa.gov/pressoffice/colapress2001.htm). ♦

*Reprinted from SSA eNews.*

### ***Barnhart Takes Charge at Social Security***

Jo Anne B. Barnhart was sworn in as the Commissioner of Social Security in a ceremony at the agency's national headquarters in Baltimore on November 9, 2001.

The Commissioner expressed her pride at being chosen to serve as Commissioner of Social Security. "I truly believe that public service is a worthy and noble endeavor, and I thank every federal employee for deciding to make a career in government," said Commissioner Barnhart. "I am proud to head an agency blessed with so many dedicated and caring employees."

Barnhart was sworn in by Larry G. Massanari, Regional Commissioner, Philadelphia. Massanari served as Acting Commissioner of Social Security since March. "She is a new leader, for a new century, where new challenges face the nation's Social Security program," said Massanari. "The SSA is very fortunate that President Bush has chosen such a talented and accomplished leader to serve as Commissioner of Social Security."

Barnhart is the 14th Commissioner of Social Security. Her term will expire on January 19, 2007.

Barnhart is a former SSA employee. She worked in the Office of Family Assistance from 1981 to 1986, first as Deputy Associate Commissioner and then as Associate Commissioner. She left to become minority staff director for the Senate Committee on Governmental Affairs.

Most recently, she has served as a member of the Social Security Advisory Board, an independent body created to advise the Congress on Social Security issues and policies. Barnhart served as a member of the Board for more than four years.

She will be responsible for administering the Social Security retirement, disability and survivors insurance programs that pay \$408 billion annually in benefits to more than 45 million beneficiaries, as well as the Supplemental Security Income program that provides cash assistance to almost 7 million people with limited income and assets. The agency has a national workforce of about 65,000 employees and 1,500 field installations.

Born in Memphis, Tennessee, Barnhart is a graduate of the University of Delaware. She lives in Arlington, Virginia, with her husband, David, and her son, Niles. ♦

*Reprinted from SSA eNews.*

### **McGreevey Signs Executive Order Creating Family Advocate Program**

Governor James E. McGreevey signed an Executive Order establishing a Family Advocate Program which will provide the families affected by the September 11th tragedy with more personalized attention, less bureaucracy and more access to the services available to them.

"Through the Executive Order, I authorized the Office of Recovery and Victim Assistance to establish the Family Advocate Program," said McGreevey. "This program will relieve families of the bureaucratic burden of navigating the system of services available to them." McGreevey announced the creation of the Family Advocate Program, which will be operating by mid-March, during a meeting with victims' families in New Brunswick. Many of the victims' families, at the last meeting held in December, told the Governor they were overwhelmed by the administrative and eligibility requirements while trying to access available financial, legal and emotional assistance. McGreevey created this program "to address those concerns and ease the burden and frustration many of the families have experienced."

"At our December 8th meeting here at Rutgers, what you said registered loud and clear. You said there was too much bureaucracy. Many services, while technically available to you, are too difficult to access and you found yourself providing different organizations the same information multiple times. Ultimately, you said we need to make the system work for you and with you, not against you."

Serving as the primary point of contact for identifying, applying for and receiving available services and assistance, Family Advocates will be assigned to specific families and injured persons on a regional basis. The trained and experienced advocates will then provide comprehensive assistance in obtaining information for the families regarding charitable and private organizations; legal, financial and mental health services; and job training and skill enhancement programs.

Eric Shuffler, Recovery Coordinator in the Office of Recovery and Victim Assistance, will be responsible for establishing a not-for-profit corporation that will administer the Family Advocate Program in conjunction with the United Way of New Jersey. The Office will also be empowered to cooperate and coordinate with private, public and not-for-profit agencies in an effort to streamline the application and qualification processes and to solicit and receive money from public sources for any recovery and victim assistance purpose. This will allow the new program to be funded through philanthropic sources. ♦

### **Health Care-Related Legislation Enacted**

**S-232**, sponsored by Senator Wayne Bryant (D-Camden/Gloucester) and Assemblyman Neil Cohen (D-Union), requires that a child support order relating to health care coverage be enforced through National Medical Support Notice and indicate the party responsible for maintaining the coverage. ♦

**A-314**, sponsored by Senators Jack Sinagra (R-Middlesex) and John Adler (D-Camden) and Assembly members Charlotte Vandervalk (R-Bergen) and Neil Cohen (D-Union), establishes a permanent commission to be known as the "New Jersey Health Data Commission." The 33-member Commission will collect and maintain health data from State government agencies or other entities. ♦

### **DDHH to Distribute Safety and Telecommunications Devices**

The Division of the Deaf and Hard of Hearing announces the availability of free smoke detector devices for the deaf (visual signaling smoke detector) to eligible residents. To acquire a free visual signaling smoke detector (one per household), you must have hearing loss, be a New Jersey resident, and have a household income of less than \$35,000 annually. Your application must be signed by a physician or audiologist, or accompanied by reports attesting to hearing loss. Smoke detectors will be given out on a first-come, first-served basis. All maintenance, liabilities, repairs, and warranties are the sole responsibility of the applicant. This program will be in effect from July 1, 2001 to June 30, 2002. For additional information, please contact: Division of the Deaf and Hard of Hearing, P.O. Box 074, Trenton, NJ 08625-0074 or call (609) 984-7281 Voice/TTY or (800) 792-8339 Voice/TTY.

The Division of the Deaf and Hard of Hearing announces the availability of free telecommunications devices for the deaf (TTY/VCO/amplified phones) to eligible citizens on a first-come, first-served basis. To qualify (one per household), you must have hearing loss or speech impairment, be a New Jersey resident, and have a household income of less than \$35,000 annually. Applications must be signed by a physician, audiologist, or speech pathologist, or be accompanied by reports attesting to hearing loss or speech impairment. Applicants must be at least 11-years-old as of July 1, 2001, and must not have received a device after July 1, 1996. This program took effect on July 1, 2001 and runs through June 30, 2002. For applications and additional information, please contact: Division of the Deaf and Hard of Hearing, P.O. Box 074, Trenton, NJ 08625-0074 or call (609) 984-7281 V/TTY or (800) 792-8339 V/TTY. ♦



## ***Drug Companies Offer Discounts to the Disabled***

**Joseph Amoroso, M.A, C.I.R.S.**

Supervisor Information and Referral Services  
Division of Disability Services

Three of the major pharmaceutical companies have announced discount programs to defray the cost of drugs to the elderly and disabled.

While many critics have been quick to call the programs "sales ploys" to entice doctors to prescribe drugs made by the participating manufactures, advocates for people with disabilities and senior citizens feel that until Medicare has a drug benefit, some relief is better than none.

Each company has designed its program differently. Below is an overview of each:

### **Novartis Care Card**

**Discount:** About 25%  
**Eligibility:** Income of \$26, 000 for Singles, and \$35, 000 for Couples, Age 65 or older or disabled.  
**Other Facts:** Only good for Novartis drugs. No other prescription drug coverage allowed  
**Contact:** 886-974-CARE or [www.novartis.com](http://www.novartis.com)

### **Glaxo Orange Card**

**Discount:** About 30%  
**Eligibility:** \$26,000 for Singles, and \$35, 000 for Couples, Ages 65 and over or Disabled.  
**Other Facts:** Only good for Glaxo drugs. No other prescription drug coverage allowed.  
**Contact:** 888-ORANGE 6

### **Pfizer Share Card**

**Discount:** \$15 per drug/month  
**Eligibility:** \$18, 000 for Singles, \$24, 000 for Couples , Ages 65 and older or disabled.  
**Other Facts:** Only Covers Pfizer drugs. No other prescription drug coverage allowed.  
**Contact:** 800-717-6005 or [www.pfizerforliving.com](http://www.pfizerforliving.com) ♦

Taken in Part from the Star Ledger February 7, 2002

## ***NJ Coalition on Women with Disabilities Awards Scholarships***

**Christine Cripps-Barker, C.I.R.S.**

Information and Referral Specialist  
Division of Disability Services

The NJCOWD held its annual Scholarships Awards luncheon at the East Brunswick Library in November 2001. Scholarships are awarded to women who are currently attending a NJ college or vocational school and who have a disability. These women have excelled in college.

Two scholarships, in the amount of \$500 each, were awarded to Jacqueline Jackson of Franklin Park and Willemarra Thompson of Penns Grove.

Ms. Jackson, a person with Multiple Sclerosis, is completing her degree at Rutgers University, majoring in Africana Studies with a minor in Psychology. After graduation she intends to obtain a position as a researcher, investigating health issues among minority women with disabilities.

Ms. Thompson currently attends Camden County College and is pursuing an Associate's Degree in Social Work.

Additionally, three savings bonds in the amount of \$50 each were awarded to Sherry Davis of Prospect Park, Lauren Snyder of Pennsauken, and Finola C. Lynch of Flemington.

The scholarship program was established in 1999 as a joint effort with the Women's Fund of New Jersey to assist women with disabilities in obtaining their educational goals. The NJCOWD hopes to expand the scholarship program each year.

The Coalition promotes greater participation of women and women with disabilities in their communities, and encourages each person to seize opportunities to bring about positive change. For more information about the Coalition or the scholarship program, please contact Dorothy McDowell, President at 732-255-2733 or via email at [DorMcD@aol.com](mailto:DorMcD@aol.com). ♦

### ***Coalition Meetings Schedule 2002 East Brunswick Library 11:30 AM***

April 3	August 7
May 1	September 4
June 5	October 2
July 10	November 6

## AROUND THE STATE

### **Atlantic County**

A Universal Design Tour House has been constructed by the Casino Reinvestment Development Authority in Atlantic City. Sometimes referred to as "lifespan design" or "transgenerational design," it goes beyond the accessible, adaptable, and barrier-free design concepts of the past. Some features of universally designed homes are adjustable to meet particular needs that change as family member's age, yet allow the home to remain marketable. The CRDA's Universal Design Demonstration Home will show how to build universal housing that can be enjoyed by everyone, but will significantly benefit a growing number of households: older households or households with a disabled family member. Because this group will continue to grow, builders will need to include universal features to keep pace with this changing consumer base. Professionals who will benefit include representatives from the housing and design industry, the health care system, the aging network, the disabilities community, plus faculty, teachers, and students in these fields. Visits will be possible for individuals as well as for groups who make arrangements in advance for viewing, tours, and meetings during the spring of 2002. The CRDA is also seeking volunteers to be tour guides. For more information, please contact: Adrienne C. Hamilton, Director of Construction, Casino Reinvestment Development Authority, at (609) 347-0500 x3219. ♦

*Reprinted from CRDA brochure, 2001.*

### **Cumberland County**

Four of the original Personal Assistance Services Program clients, Marty Manuel, Shirley Langley, Pablo Viera, and Carolyn Goodwin, were honored at a celebration of the program's fifteenth anniversary in Cumberland County on December 17, 2001. This program, which has made it possible for them to work, attend college, or be community leaders, is headed by Reba Chonofsky. Michael Nuskey, program administrator for the state Personal Assistance Services Program, commended the staff members of the Cumberland County program. He said approximately 500 people with disabilities, ages 16 to 65, are enrolled in the statewide program. Chonofsky, who said she has 14 consumers currently enrolled in Cumberland County, has been the coordinator since the inception of the program in the county. She told how the program enables those with disabilities to be in control of their schedules and to be more independent. "You have all been a super inspiration in my life," Chonofsky said. ♦

*Reprinted from Atlantic City Press, December 2001.*

### **Morris County**

Effective the first Saturday in November 2001, and each first Saturday of the month thereafter, there will be a free clothing giveaway at the United Way of Morris County Annex. Their inventory includes women's sizes 4 through 12 only (women's sizes 14 and up are not included), and most men's sizes. They are very overstocked in the smaller women's

sizes. Agency referral is required to participate. Clients who wish to participate must bring a copy of the completed Referral Form with them to their appointment—NO children are allowed at the Annex. ♦

*Reprinted from DAWN newsletter 2001.*

### **Maslansky Joins Cerebral Palsy of New Jersey**

Cerebral Palsy of New Jersey is pleased to announce that Debra Maslansky has been named the new Director of Case Management Services, and will also be directing their substance abuse prevention program. Maslansky comes to her new position with twenty years of experience in the field of mental retardation and developmental disabilities, including traumatic brain injuries, and successful professional tenures at the Brain Injury Association of New Jersey, Substance Abuse Resources, and the ARC/Middlesex. In April 2001, Cerebral Palsy of New Jersey honored her with the Elizabeth Boggs Disability Advocate Award in recognition of her involvement in the production of the video "Silent Storm." She is also a founding member of the National Association on Alcohol, Drugs and Disabilities, and helped to establish the New Jersey Coalition on Disabilities and Addictions, serving first as a volunteer board member, a committee chair and then as statewide coordinator. Maslansky is a graduate of Boston University with a Bachelor of Science in Special Education, and Brooklyn College with a Master of Science Degree in Counseling and Guidance. For questions about advocacy/case management services, or to arrange a free seminar for your organization on substance abuse prevention, please contact Cerebral Palsy of New Jersey at 888-322-1918 or 609-392-4004. ♦

### **Kessler Seeks Those with SCI for Study**

Kessler Medical Rehabilitation Research and Education Corporation is presently seeking people with Spinal Cord Injuries to take part in a weight loss and exercise study.

Eligible Participants must be:

- At least one year post injury
- Between the ages of 18 and 55
- Have an injury between the level C5 and L12

All services are free of charge, and participants will be compensated for their time and travel, provided they have their own transportation.

Interested parties should contact Dr. Sue Ann Sisto at 1-888-648-0296 x 6888 or via e-mail at [ssisto@kmrrec.org](mailto:ssisto@kmrrec.org).

***Around, continued on page 14***

### New Jersey and Olmstead: "A Work in Progress"

**William A. B. Ditto**

Director  
Division of Disability Services

The Olmstead vs. L.C. Supreme Court decision is of tremendous importance to the disability community. This landmark decision affirms the rights of people with disabilities to live in the community and to make lifestyle choices based on individual preferences. New Jersey, like many other states, has taken positive steps to assure that people of all ages with disabilities have options available to them as an alternative to institutional care. Most people would prefer to live in the community. Although our state has already undertaken many initiatives to strengthen capacity and improve our system of community supports and services, we acknowledge that more can, and must, be done.

With this in mind, and at the urging of the advocacy community, New Jersey convened an Olmstead Stakeholder's Task Force in November 2000. The group is composed of consumers, advocates, government agency representatives, providers and other interested parties. The group has provided invaluable input and guidance to the state as it wrote the New Jersey Olmstead Planning document, "Achieving Community Integration for People with Disabilities." Although there were certainly areas of disagreement and controversy along the way, I was truly impressed at the overall spirit of collaboration and cooperation among this diverse group of stakeholders. The plan will be reviewed quarterly and updated and changed to reflect accomplishments, progress, obstacles and environmental changes. Thus it is a "work in progress" – ever evolving and subject to constant revision. Shortly it will be released to the public for the first time, following review by Governor McGreevey's office.

New Jersey was fortunate to receive a three-year \$2 million "Real Choice Systems Change Grant" from the federal government in October 2001. This grant award, one of the highest in the nation, will allow New Jersey to improve our long-term system of care and supports for people with all types of disabilities. Major areas of activity under the grant are housing, improved individual assessment practices, front line staff recruitment and retention, quality assurance and other pilots, demonstrations and innovative projects.

In subsequent issues of **VISIONS**, my staff and I will be providing you with additional information on the Olmstead Plan and our progress with the grants. Please feel free contact me if you have any questions. ♦

### Search Engines: Information Lost and Found

**Nancy L. Mangold**

Information and Referral  
Division of Disability Services

For people with disabilities, the Internet is an essential source for obtaining useful information specifically about an illness or disability, or just coping with the changes in everyday life that come from having a disability. Unfortunately in some cases, the amount of information that one encounters is overwhelming and may be frustrating to use. The purpose of this article is to explain how the Web can help you find information concerning any aspect of your disability in an effective manner. For most disabilities, an organization, such as the MS Society, has a Website that is dedicated to specific information about that particular disability. These sites are usually the most current, and are maintained by professional webmasters. People with rare disabilities may have some difficulty in finding information on the web. If all else fails, I suggest stopping at the NORD (National Organization of Rare Disorders) Website at [www.nord.org](http://www.nord.org), or going to Google.com and typing in key words.

If you are unsure how to begin your search, or are searching for a general disability site, I have listed some of the more popular ones below with some general comments about each one.

**Halftheplanet.com:** Halftheplanet.com is a website that deals with legal or employment issues involving individuals with a disability. There is a section that quizzes you on your knowledge of the Americans with Disabilities Act. The site offers tips on finding a job, preparing a resume, and techniques for interviewing.

**Ilusa.com:** This site is a great source for issues regarding the disabled in today's media. Upon entering the site, you are greeted with a picture of the day, and view the latest headlines that deal with related news events involving those who are disabled. All their articles are excerpts taken from CNN, The New York Times, Los Angeles Times, and the BBC.

**About.com:** When you first glance at this site, you might think that it does not pertain to issues regarding disabilities or alternative therapy. You need to find and 'click' on the "Health and Fitness," selection which, will lead you to a list of many disabilities and chronic illness topics. This is a great site to explore alternative therapies, subscribe to on-line newsletters, and offers a place to purchase durable medical equipment such as motorized wheelchairs. Overall, with a little effort on your part, this site offers a wealth of information.

*Web, continued on page 15*

### Understanding and Utilizing Mutual Aid Self-Help Groups

**Barbara J. White**, State Program Coordinator  
New Jersey Self-Help Group Clearinghouse

During the course of a day, you probably come in contact with individuals who are facing new disabilities, difficult life challenges, personal losses, or other stressful life situations. In addition to the services of your agency, perhaps there is also a local self-help group that can be drawn upon for added support. Possibly you know someone in need who lacks social, familial or financial support. Such a person might well benefit from the sense of community gained from a self-help group, or who would welcome the financial accessibility of a group. Self-help groups can be a valuable, free resource for those who are seeking comfort, hope and strength while dealing with life's challenges.

#### UNDERSTANDING THE BENEFITS OF SELF-HELP GROUPS

The benefits of self-help groups are plentiful, and the research documenting their value is escalating. Although self-help groups are not meant to replace professional therapy, they can act as a valuable, free adjunct to professional services. By the very nature of groups being comprised of peers, members gain a unique "sense of community" that is difficult to obtain from others who have not shared similar challenges. When a person comes face-to-face with a stressful life situation (e.g., a disability, personal loss, or medical or emotional diagnosis), inner feelings of inadequacy, self-doubt, or fear may emerge. Listening to others in the group who have faced and overcome a similar experience can validate an individual's innermost feelings, and impart a much-needed sense of normalcy and self-acceptance.

Self-help groups also empower members with various levels of knowledge. Through the exchange of practical information, coping skills, and both experiential and specialized knowledge, self-help group members can become well-informed and educated about their disability or situation. In addition, members are exposed to positive role models: others who have faced similar difficulties, yet learned the tools to overcome or accept them. A well-informed client, armed with proven techniques designed for dealing with a particular problem, is more apt to flourish.

As persons involved in the "helping" professions have experienced firsthand, it is nearly impossible to reach out to help another without simultaneously helping yourself. At the crux of self-help groups lies the power of "mutual aid:" people helping people. This "helper therapy," so intrinsic in groups, gives members an increased sense of self-worth and meaning.

However, one of the most powerful aspects of self-help groups, especially intrinsic in groups dealing with physical and psychiatric disabilities, is their capability for building the platforms on which members can advocate for needed services. Over the years, the Clearinghouse has assisted many individuals diagnosed with newly found disorders to start desperately needed support networks. When faced with a disorder that has neither been addressed nor recognized by the research community, a person feels utterly alone in their plight for information and hope for the future. But, when banded together in a self-help group, these individuals together form a louder, more resonant voice. Many national organizations (e.g., Huntington's Disease Society of America) were begun from the despondency felt by someone who needed services and information that did not yet exist.

#### UTILIZING AND SUPPORTING SUPPORT GROUPS

As a professional, there are several ways in which you can support the development and utilization of self-help groups. One obvious way is to become familiar with the benefits and availability of groups in order to make appropriate referrals to them. For over twenty years, the mission of the New Jersey Self-Help Group Clearinghouse has been to help people find and form all types of mutual aid self-help groups. Emerging from a small compilation of well-used index cards, the Clearinghouse database has evolved into a comprehensive referral base of over 4500 self-help group meetings in New Jersey alone. These groups deal with a vast array of issues including disabilities, abuse, addictions, health, mental health, bereavement, family and parenting concerns. Group formats run the gamut from highly structured, professionally run groups, to loosely formatted social groups. Although some groups follow the 12-step program developed by Alcoholics Anonymous, most have designed their own unique set of guidelines. Another difference amongst groups is the specificity of their focus. Some groups are very open while others are extremely focused.

The professional community can assist groups, not only by using them as a referral source, but by also lending their expertise and encouragement to new and existing groups. Many groups seek the advice and knowledge of a professional who would be available to guide them. This partnership can be rewarding for both the professionals and the members of the group.

#### THE SERVICES OF THE NEW JERSEY SELF-HELP GROUP CLEARINGHOUSE

The New Jersey Self-Help Group Clearinghouse is funded through the NJ State Division of Mental Health Services, and sponsored by Saint Claires Health Services. Each year, the Clearinghouse fields over 14,000 calls from persons looking for group support. For those interested in starting groups, the Clearinghouse provides free telephone consultation, "how-to" literature, and various workshops focusing on issues pertinent to group development. For information about self-help groups or on our services, please contact the NJ Self-Help Clearinghouse at 1-800-367-6274 or (973)326-6789 or visit our website at [www.selfhelpgroups.org](http://www.selfhelpgroups.org) ♦



## GUEST AUTHOR

### ***Substance Abuse Prevention Issues for Persons with Disabilities***

**Debra Maslansky**  
Cerebral Palsy of New Jersey

Programmatic, architectural, communication and attitudinal barriers cause people who are deaf, blind, physically disabled, developmentally disabled and those with cognitive limitations to have limited access to alcohol/drug abuse prevention and treatment programs. In light of the fact that most people with disabilities live and work in the mainstream of our communities, they are not immune to the problems associated with substance abuse merely due to their disability. There is growing evidence that people with disabilities are at equal or perhaps greater risk of experiencing an alcohol or other drug problem than the general population. Research clearly shows that substance abuse directly contributes to the incidence of spinal cord injuries and traumatic brain injuries.

Perhaps one of the most critical problems facing the individual who has a disability and a co-existing substance abuse problem is lack of awareness of the overlapping issues of concern and opportunity for cross-training and exchange of information between the two professional fields. Disability service providers need to become better observers of high-risk behavior and learn how to make early identification and referral. Substance abuse professionals need to diminish attitudinal barriers, comply with the ADA, increase cultural sensitivity and disability awareness, and modify treatment approaches when needed.

Individuals are considered at-risk when a particular circumstance makes them vulnerable to alcohol/drug problems. Clearly, people with disabilities may abuse alcohol or other drugs for all the same reasons as their non-disabled peers. However, there are a number of other reasons, directly related to the disability, which might contribute to the increased risk:

- Prescription drug abuse, and mixing with alcohol
- Inadvertent enabling by well-meaning family, friends and professionals
- Adjustment to a new disability
- Social isolation, lack of recreation or social opportunities
- Lack of transportation and employment options
- Insufficient or ineffective substance abuse prevention / education curriculum received during school years. ♦

Since 1985, there has been an initiative in New Jersey, and more recently around the country, to improve and increase access to substance abuse prevention and treatment services and program materials for people with all types of disabilities. For more information on this topic, please call Cerebral Palsy of New Jersey at 888-322-1918 x518. ♦

#### ***Care, continued from page 4***

There are several specific requirements that are part of the stage three appeal. In order to file properly, you must complete the appropriate form (as supplied to you by the managed care plan), and include a consent to obtain medical records, an application fee, and a copy of the "Summary of Insurance Coverage" from your managed care plan member handbook. The information must be mailed to the Office of Managed Care in the New Jersey Department of Health and Senior Services. If the IURO accepts your appeal for review, they will issue a non-binding recommendation within 30 days to both the health plan and to you or your doctor. The managed care plan is required to inform the State within 10 days if they will follow the recommendation of the IURO.

**For Medicare and Medicaid Beneficiaries:** In addition to the appeals process described above, if you are a Medicare or Medicaid beneficiary in managed care, you have additional appeal processes available under federal law which you can use in lieu of the appeals procedures described above. There is a five-step appeal process applicable to Medicare, and the right to a Fair Hearing under Medicaid.

For more information about the appeals process, please call the Community Health Law Project at (973) 275-1175. ♦

*Reprinted from "To Your Health Bulletin" of the Community Health Law Project, August 1999.*

### ***New Jersey Managed Health Care Consumer Assistance Program***

The New Jersey Managed Health Care Consumer Assistance Program (MHCCAP) is staffed by the Community Health Law Project and New Jersey Protection & Advocacy, Inc. and sponsored by the Department of Health and Senior Services. It educates consumers of managed care about their rights under both commercial and government-sponsored managed care plans. MHCCAP distributes a free consumer handbook on consumers' rights and responsibilities under managed care.

El Programa de Asistencia al Consumidor Para el Cuidado Médico Administrado de New Jersey también está disponible en español. ♦

Toll-free Helpline: **(888) 838-3180**

## Remembering Colleen

### Tributes from Colleagues

"In September 1988, when Colleen Fraser left the Union County Office for the Disabled to become Director of Advocacy for the United Cerebral Palsy Associations of New Jersey, she encouraged me to apply for the job as Director of the Office for the Disabled. I was reluctant at first but she was very supportive and convinced me to go for it. She also worked behind the scenes to persuade the County to hire me. Through Colleen's efforts, I got the job and I've been Director of the Office for the Disabled for the past 13 years. Colleen touched my life and her life touched so many other lives."

**Charles Newman**

"John Steinbeck developed a theory; *Once a cause is given direction, the group takes on a life of its own.* I can't imagine how limited the conscience of the disability movement would have been if Colleen Fraser had not given the group her vision and direction."

**Lydia Kirschenbaum**

*Around, continued from page 10*

## Mercer County Forms Task Force

Mercer Council on Alcoholism and Drug Addiction operates one of the Task Forces of the New Jersey Prevention Network's Disabilities and Addiction Project. The other two Task Forces are located in Sussex and Union Counties. As a Regional Task Force, Mercer works cooperatively with the counties of Burlington, Camden, Gloucester, Salem, Cumberland and Cape May. The Project is dedicated to insuring that New Jersey citizens who are deaf or hard of hearing or with other disabilities have access to, and receive, the most appropriate treatment for substance abuse. For more information, contact Betty Broecker, Disabilities Coordinator at 609-396-2170 TDD, via the NJ Relay Service at #733 or via e-mail address is [bettymcada@aol.com](mailto:bettymcada@aol.com) ♦

### Quote Corner

*"Beyond proclamations of pride, deaf and disabled people have been uncovering and formulating sets of alternative values derived from within the deaf and disabled experience...They declare that they prize not self-sufficiency but self determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community."* - **Paul K. Langmore**

## How Have You Dealt with September 11?

*Project Cope has resources and is seeking stories*

Project Cope is a national clearinghouse for resources in the aftermath of disaster, with a special emphasis on special and vulnerable populations including:

- ♦ Children and Adults with disabilities
- ♦ Children with prior traumas, including foster children
- ♦ Families and Caregivers

The Project Cope website can be found at [www.projectcope.net](http://www.projectcope.net) ♦

## September 11<sup>th</sup> Information

The following is a list of important hotline numbers and websites for New Jerseyans to contact for information relating to the September 11<sup>th</sup> attacks:

- **1-866-NJ-CRISIS:** For NJ families wishing basic information and to report a missing person
- **1-866-483-5137:** FBI hotline for information about the September 11<sup>th</sup> terrorist attacks
- **1-800-331-0075:** US Dept. of Justice Office of Victims of Crime
- **1-800-969-5300:** University Behavioral Health Care; free grief and anxiety counseling
- **1-800-277-BIAS:** For victims of bias crime
- **1-609-882-2000 x6040:** State of NJ Emergency Operating Center
- **1-800-GIVE-LIFE:** American Red Cross blood donations
- **1-800-HELP-NOW:** American Red Cross monetary donations
- **1-800-SAL-ARMY:** Salvation Army monetary donations
- **1-800-286-6528:** Governor's Office of Volunteerism
- [www.state.nj.us](http://www.state.nj.us): State of NJ website with updated crisis information
- [www.nyc.gov](http://www.nyc.gov): NY City website with crisis information, traffic and closings
- [www.panynj.gov](http://www.panynj.gov): Port Authority website with PATH, bridge and tunnel information
- [www.mta.nyc.ny.us](http://www.mta.nyc.ny.us): Metropolitan Transit Authority of NY info for subway, bridges, and tunnels
- [www.njtransit.com](http://www.njtransit.com): NJ Transit information
- [www.uwnyc.org](http://www.uwnyc.org): United Way of NY
- [www.redcross.org](http://www.redcross.org): Red Cross

## Web, continued from page 11

**Cripworld.com:** This website is a place to look for products such as magazines and videos that are marketed to those who have disabilities and who want to maintain a healthy, active lifestyle. There is also a section on how to build websites and will lead you to sites that will quickly teach you the basics. Unfortunately, this site is definitely a work in progress. Many options, such as the travel and community sections, will lead you to pages that cannot be accessed.

**ICanOnline.com:** This website purports itself as a community that can foster relationships, and give guidance to those who are disabled. The members of the web-site team actually are friends with one another. Their message board is periodically changed to update the hottest topics, and is staffed by trailblazers to lead us with their expertise on various issues involving money and finance, education, employment, sex, and much more. It also the home of "On A Roll" an informative radio talk show, heard only on public radio, which only deals with issues involving the disabled. You can even listen to an archive program while searching the site.

Please email [nmangold@dhs.state.nj.us](mailto:nmangold@dhs.state.nj.us) if you would like to share a Website, or have any comments/suggestions, Happy Surfing ♦

## Wired on Wheels Promotes Access

A website has been set up to promote restaurant accessibility. *Wired on Wheels* gives restaurant patrons the opportunity to make a difference by reviewing eating establishments by standards that matter to people with disabilities: "Will the bathroom accommodate a wheelchair?" "How easy is it to navigate between the tables?" "Do they have alternative format menus?" "Are there any steps at the entrance?"

If you have a disability or are non-disabled, but have dined out with friends who have disabilities, consider supporting this site by reviewing some of your favorite eateries at [www.wiredonwheels.com](http://www.wiredonwheels.com). Help build a comprehensive national directory that will enable diners with disabilities to avoid frustration and find the restaurants that are worth the trip. ♦

## Disabled Internet Use Grows

A Harris poll released in mid-January says 35 percent of people with mobility impairments are Web surfers. The poll also reports that 43 percent of people with visual impairments and 39 percent of people with cognitive or learning disabilities regularly use the Internet at home. The combined percentage of disabled users averages out to 38 percent, more than five times the 7 percent who were using the Internet in late 1998.

At 56 percent, non-disabled people still use the Internet more than disabled people, says Gerry Hendershot, Ph.D., Senior

Research Advisor for the National Organization on Disability, which commissioned the survey. However, says Hendershot, "If Internet use by persons with disabilities continues at the same growth rate, it should match the rate of other [non-disabled] users in a few years." ♦ Taken from New Mobility Online

## VSA Sponsors "Partners in the Arts' Festival

Partners in the Arts is a festival that fosters the integration of individuals with and without disabilities in a celebration of the arts.

The day long event is to be held at Middlesex County College in Edison on May 15, 2002.

Exhibits will showcase Performance Art, Visual Art, and Interactive Activities.

Admission to the event is free. Brown Bag lunches are suggested. The facility is wheelchair accessible.

For information, call (732) 745-3885 or e-mail [info@vsanj.org](mailto:info@vsanj.org)

## NOTA BENE

Congratulations to **Anita Smith** of Home and Community Services on her November 2001 marriage to Marco Lobrano.

**Christine Cripps-Barker**, of Information and Referral Services, has been named Chairperson of the Research Workgroup for the Health Care and Women with Disabilities Steering Committee.

**Joseph Amoroso** of Information and Referral Services and Division Director **William A. B. Ditto** have co-authored an article entitled *Innovations in Information and Referral: The Disability Community*. The article was published in the Journal of the Alliance of Information and Referral Systems, Volume 23.

Congratulations to **James Jenkins** and his wife Monica on the birth of their son, Javon, who entered the world on December 14, 2001.

**Carolyn Selick** of the Personal Preference Program became an aunt twice with the birth of Emily Alice A'Hearn on July 12, 2001 and Michael Lawrence Rogers on December 11, 2001.

## Personal Preference Program and CAU Gear Up for Final Enrollment Push

### **Carolyn M. Selick**

Program Manager, Personal Preference Program  
Division of Disability Services

I am happy to announce that Community Access Unlimited (CAU) has expanded its role beyond the fiscal intermediary service for the Demonstration, to include enrollment of eligible participants. Enrollment Specialists from Community Access Unlimited are now enrolling participants throughout New Jersey. The Enrollment Specialists will give each potential participant detailed information about Personal Preference to allow consumers to make an informed decision about joining the program.

Marketing and enrollment of the program will continue until June 30, 2002, ending a process that began in late 1998.

Personal Preference, New Jersey's Cash & Counseling Program, is a national research and demonstration project sponsored jointly by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services. Using the concept of "consumer direction," it allows elderly and disabled Medicaid-eligible recipients to direct and manage their personal care services. Through a monthly cash allowance, participants in the Demonstration will work with a consultant to develop a Cash Management Plan by which they will decide the services they need and the individuals and/or agencies they wish to hire to provide the identified services. The program requires greater consumer responsibility but offers the participants greater control, flexibility and choice.

If you would like more information about the Personal Preference Program, please call the Division of Disability Services (toll free) at 1-888-285-3036.

## Consumers Endorse Personal Preference Program

Agencies could never send anyone who could lift/transfer me. I have the opportunity to interview and choose who I want to work for me." **George Caruso**

"Aides wouldn't always show up and the agency wouldn't be able to find a replacement. I can just call my employees and don't have to worry about having help. I can sleep at night."

**Michael Chellimi**

## Medicaid Buy-In Changes Name to NJ WorkAbility

### **Pablo E. Viera**

Program Manager, NJ WorkAbility  
Division of Disability Services

The Medicaid Buy-in Program has changed its name to NJ WorkAbility. The name change and the associated slogan, "Health Care that works with you," will be the cornerstone of an upcoming outreach campaign.

Program staff, in conjunction with other state and non-profit organizations, are planning several regional forums. The forums will address issues related to increasing opportunities to help people with disabilities go to work.

A Transportation Workgroup has been formed and charged with developing a five-year plan to address transportation barriers for people with disabilities, who are seeking employment or are actively employed. Updates from the Workgroup will be forthcoming in subsequent issues of **VISIONS**.

The rules for the NJ WorkAbility Program were published in the January 22, 2002 edition of the New Jersey Register. There is a 60-day period for public comment.

February 2002 marks the one-year anniversary of the program. To date, we have enrolled 340 people. The program staff and I are energized and look forward to the future.

If you have questions or need information, please contact the Division of Disability Services (toll free) at 1-888-285-3036. ♦

## Federal Poverty Level Changes Effect NJ WorkAbility Criteria

### Unearned Income

2001	Single \$716/Couple \$968
2002	Single \$739/Couple \$995

### Earned Income

2001	\$42,950/per year \$3,579/per month
2002	\$45,084/per year \$3,757/per month



## ***Preparation for Disaster Makes the Difference***

**Marlene L. Hester, C.I.R.S.**

Information and Referral Specialist  
Division of Disability Services

The events of September 11, 2001 have caused many of us, disabled and non-disabled alike, to reluctantly consider what we would do if we were in an area that suddenly became catastrophically damaged or contaminated. The best way to convert a sense of vulnerability into a feeling of control is to develop a plan of action. For a person with a disability, having a plan of action that includes an emergency kit, an information list, and a network of people who know your needs and location, can make a big difference if a disaster occurs.

The reality is that almost any emergency evacuation shelter will *not* have medical personnel, personal care attendants, pharmaceuticals, hoist lifts, medical supplies beyond first aid kits, sterilizing agents, food to meet special dietary needs, food for service dogs, or sign language interpreters. Nor will many friends' and relatives' homes, for that matter. While each person who is disabled or who is primarily responsible for the care of a person with a disability has the responsibility of determining what the specific plan should be, the following suggestions indicate the kinds of steps that can be taken to prepare for disaster:

- Contact your local Red Cross, your municipal or county disaster preparedness coordinator, and the management of your apartment building, if applicable, to let them know that you will have special needs if a disaster occurs. Talk to them about what their disaster plan is for you and for the area in which you live.
- Develop a network of people who know your needs and location, who will be able to assist you or alert emergency personnel on your behalf.
- Prepare a complete kit of supplies that you will need – if you use prescription medications, include a few days' worth in the kit and replace them periodically before they expire.
- Prepare an information list, especially if you have considerable medical needs, which details your personal care needs, contact information for your doctors and care providers, and a med chart.

We have all heard the stories of people with disabilities residing in apartments close to Ground Zero, who were trapped alone for days when electric and phone services were lost, and the area was declared a restricted zone. The Red Cross, who organized disaster response teams for a door-to-door search of people in need of help, found many

people with physical, cognitive, and psychiatric disabilities who had been waiting for days for someone to come to their aide. The team found one mobility-impaired woman with MS who heard the buildings come down but then lost electrical power and could not watch television to find out what was happening. She sat in her dark apartment for two days, unable to use the elevator, phone for help, bathe, cook, get to the toilet, or get information about the outside world.

The Internet has a number of helpful resources for anyone with a disability who would like to develop a practical disaster preparedness plan. The Red Cross publishes a comprehensive 48-page booklet, *Disaster Preparedness for People with Disabilities*, which includes a personal survey and a needs checklist. It can be downloaded and printed out directly from [www.redcross.org](http://www.redcross.org). Copies of the booklet or an audiocassette version can also be requested by calling your local Red Cross chapter. The Federal Emergency Management Agency (F.E.M.A) provides a good basic overview of the subject at [www.fema.gov](http://www.fema.gov). The National Organization on Disability's website, [www.nod.org](http://www.nod.org), has a great deal of disaster-related information which can be accessed by going to their search engine and typing in keywords "disaster preparedness."

Obviously no plan can guarantee safety or avoidance of inconvenience. But in a chaotic disaster situation it may not be possible to gather what one needs, make necessary contacts, or even think clearly. There is no better time than the present to develop a plan that can greatly enhance the chances of successfully coping with a disaster. ♦

## ***Flower Power Alive and Well at RIL***

The 60s are alive and well at Resources for Independent Living. People with disabilities are volunteering to participate in a program called "Flower Power." The program is based on the idea that sometimes the best way to get what WE need is to give something away to others.

A complete flower arranging work room and display room have been donated by Richard Welsh, owner of the Crossings of Riverside. Professional floral arrangers donate time to teach flower-arranging skills to people with disabilities. Local businesses donate flowers to be used in arrangements. People with disabilities volunteer to arrange the flowers. The arrangements are then delivered to people who would enjoy knowing that they are important, valued, and respected by the people in the community who built the arrangements for them. If you would like to participate in the program, call Cathy at 856-764-2745. ♦

## **Education by the Numbers: Good News for Children with Disabilities**

More children with disabilities are being educated in local schools rather than being sent to separate institutions, according to a new report that looks at 25 years of educating children with disabilities. Among the findings are:

- In 1970, only 20 percent of children with disabilities were educated in regular schools. In 1976-77, after laws changed, the number rose to 93 percent, and by 1997-98 has risen to 96 percent.
- The number of infants, toddlers, and preschoolers receiving services through the Individuals with Disabilities Education Act rose from 366,000 in 1987-88 to 793,000 in 1999-2000.
- The percentage of students with disabilities graduating from high school increased from 51.7 percent in 1993-94 to 55.4 percent in 1997-98.
- The percentage of students with disabilities taking the SAT rose from 1.2 percent in 1993 to 1.9 percent in 2001. The percentage taking the ACT has risen from 1 percent in 1990 to almost 3 percent in 2000.
- The percentage of college freshmen reporting a disability increased from 3 percent in 1978 to 9 percent in 1998.
- The number of special-education teachers and related personnel nationally has increased from 331,000 in 1976-77 to 800,000 in 1997-98

(Source: Educating Children with Disabilities: The Good News and the Work Ahead 2002 by the American Youth Policy Forum and Center on Education Policy).

This report is on the Web at [www.ctredpol.org](http://www.ctredpol.org)  
Taken from Atlantic City Press March 4, 2002

## **Office of Minority and Multicultural Health Offers Graduate Fellowship**

The Office of Minority and Multicultural Health has announced the summer 2002 Cook and Rutledge Fellowships.

The two fellowships are open to New Jersey Residents pursuing graduate degrees in medical science, law or Masters in Public Health programs.

Each fellowship provides a stipend of \$5000. Successful candidates must complete a supervised ten-to-twelve week project with the Department of Health and Senior Services. Applications are due April 1, 2002.

Questions may be directed to Sandra Christofori at 609-292-6962 or [sandra.christofori@doh.state.nj.us](mailto:sandra.christofori@doh.state.nj.us).

*Resources, continued from page 6*

## **From Charity to Confrontation**

**Marlene L. Hester, C.I.R.S.**  
Information and Referral Services  
Division of Disability Services

In their preface, sisters Fleischman and Zames quote a book by Elizabeth Young-Bruehe, The Anatomy of Prejudice, in which the author addresses "the four prejudices that have dominated American life and reflection in the past half-century – anti-Semitism, racism, sexism, and homophobia." The fact that disability discrimination is not even mentioned, say Fleischman and Zames, is an example of why the ongoing disability rights movement has been so greatly needed and, at the same time, so daunting to push forward.

Throughout The Disability Rights Movement: From Charity to Confrontation, the authors demonstrate that one of the greatest challenges of the movement has been to convince mainstream America that such a movement was even necessary. So many of the "protections" that have been "provided" to people with disabilities, from sheltered workshops to institutionalization to segregated education to not having to work, have historically been largely viewed as helpful benefits that were already enhancing the quality of life for people who would never be able to truly experience full and self-directed existences. The few token heroes who arose as a result of these "benefits" were not so much expected to demonstrate possibilities to other people with disabilities, show the authors, as they were to demonstrate to non-disabled people the value of continuing to be charitable.

Many individuals' stories throughout this book bring to life the evolution of consciousness of people with disabilities, which has led to vast changes in daily American life. The reader is introduced to Judith E. Heumann, founder of the New York civil rights organization "Disabled in Action" U.S. Assistant Secretary of Education under the Clinton Administration, and a quadriplegic wheelchair user. Her first attempt at entering the workforce was thwarted in 1970, when she attempted to obtain a teaching certificate from the New York City Board of Education and was denied based upon her "paralysis of both lower extremities." Apparently she failed the board's medical test because she did not answer their many invasive toileting questions to their satisfaction, and they surmised in her presence that "she wets her pants."

The authors have produced a comprehensive history of the struggle for disability rights in the United States which will provide a wealth of information for anyone wishing to become more knowledgeable about the movement. Required reading for any advocate.

Charity to Confrontation Doris Zames Fleischer and Frieda Zames 2001, Temple Univ., ISBN 1-56639-811-8

### ***Hero, Continued from page 5***

However, no one heard her. She also tried scratching at the door, but our neighbors were not home. At this point my side was beginning to hurt from the pressure that I was putting on it, and I was becoming a little light headed due to my positioning. I gave Tess the command to heal next to my chair. I placed my elbow on top of her head in order to relieve the pressure from my side. This was a great relief. Tess and I stayed in that position for almost three hours. She never complained or tried to move away. She assisted me in the regal and courageous manner, which was true to her nature. Later at the emergency room I found that I had some bruised ribs and was dehydrated. This is a far better outcome than I might have experienced if Tess had not been there.

Tess became my hero that day and every day after that. We had many journeys in the years following. I attended law school. Tess went with me, sleeping through most classes. When I received a job at Rutgers and then at the Community Access Unlimited, she was there to assist. Finally, when I became the Deputy Executive Director of the Office on Disability Services, Tess was also hired.

All of this changed during one staff meeting. During the meeting, Tess had a grand mal seizure. I immediately did what we were taught to do during team training! I checked the surrounding area to make sure she had not eaten chocolate or any other poisonous material. I found nothing. Many medical examinations and seizures later, Amy and I found out that Tess had a brain tumor that was rapidly growing. The doctors of the New York City Animal Hospital explained that Tess had about six months to live and that they may be able to prolong her life to one year if the growth was removed. We brought Tess into the animal hospital exactly one week from the day that she marched in the St. John the Divine Animal Blessing ceremony. She had been part of this ceremony for over 6 years and we had made a conscientious effort to have the operation done after the blessing. Our feelings when we dropped Tess off at the animal hospital were of hope and sorrow. Giovanni and my then 3-year-old daughter Maya gave Tess a big hug. Amy and I gave her a hug and kiss and I promised that as soon as this was over I would bring her favorite treat, vanilla ice cream. Before we parted, Tess picked up her leash and handed it to me. This would be her last act as a service dog.

A week later, my wife and I were asked make a decision about Tess. For all intents and purposes, Tess was already gone. She took 3 licks of her ice cream and then died. During her memorial service, I looked around and was pleased by how many people knew and loved Tess. I was particularly moved when Giovanni stood in front of the audience and read a poem about dogs. Tess touched everyone in one way or another.

Today, I am fortunate enough to have a new hero named Janus, a spunky Lab/Golden mix. He will open doors literally and figuratively, and we will form the kind of bond that makes the service dog and handler a team. I have shared this story because it exemplifies what an assistance animal and handler can accomplish together. The bond between humans and animals goes back thousands of years; but we have only recently discovered the enormous contribution that they can make toward independence. ♥

## ***Types of Assistance Animals***

**Service Dogs** - come in a variety of shapes and sizes. The trend tends to be the use Labs or Golden Retriever's or a mix of these breeds. Service dogs do everything from pull manual wheelchairs to retrieve dropped items or open doors. Most service dogs learn about 65 commands by the time they are trained with their handler. A service dog can be further trained for individualized tasks like assisting the handler with removing his or her socks.

**Hearing Dogs** - breed varies by program, Border Collies and Welsh Corgis are favorite breeds. Dogs of this type perform tasks such as alerting the handler when someone calls their name, the phone rings, a baby cries, or a fire alarm is sounded. Hearing dogs adjust to their environment and learn exactly what is needed of them by the handler.

**Facility Dogs** - breed varies greatly. These dogs provide incentives to motivate the individual with a disability to meet their goals. Often used in an institutional or therapeutic setting.

**Companion or Social Dogs** - dogs vary in breed, similar to facility dogs. These dogs usually work via a team approach when a parent of a child with a disability usually acts as the main handler. Some of these dogs do tasks similar to that of service dogs. Their main goal is to motivate, encourage, and support independence of the individual with a disability. ♦

## ***Service Animal Information***

Canine Companions for Independence  
[www.caninecompanions.org](http://www.caninecompanions.org) 800-572-BARK

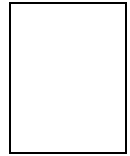
Service Animal Registry of America (SARA)  
<http://affluent.net/sara> 972-354-2520

Delta Society  
[www.deltasociety.org](http://www.deltasociety.org) 425-226-7357

United States Department of Justice  
[www.usdoj.gov:80/crt/ada/animal.htm](http://www.usdoj.gov:80/crt/ada/animal.htm)

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Division of Disability Services  
PO Box 700  
Trenton, NJ 08625-0700  
(888) 285-3036  
TTY: (609) 292-1210



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# **V I S I O N S**

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Professionals in the  
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